

1 **Experiences and nutrition support strategies in dementia care: lessons from family carers.**

2 **Abstract**

3 **Aim:** To explore the perceptions of family carers of people with dementia, with emphasis on  
4 feeding-related challenges, burden of care attributable to nutrition support and practical  
5 strategies developed to address these challenges.

6 **Methods:** A descriptive exploratory qualitative study was undertaken using semi-structured  
7 interviews from a sample of fourteen family carers of non-institutionalised individuals with  
8 dementia living in Queensland, Australia. Interviews explored carers' perceptions of feeding  
9 and nutrition support, associated burden and strategies applied to address nutrition-related  
10 challenges. Interview transcripts were thematically analysed using open-coding and  
11 triangular analysis.

12 **Results:** Family carers described a range of feeding and nutrition challenges experienced,  
13 including physiological, cognitive, emotional, functional and/or behavioural challenges.  
14 Carers described the strategies they used to address feeding challenges, which sometimes  
15 contributed to carer burden. Family carers felt uninformed and unsupported with respect to  
16 nutrition-related care by health professionals. Loss of food intake, weight loss and wasting  
17 were reported to be sources of considerable anxiety for the family carers. Most family  
18 carers reflected that their experience of nutrition care had been difficult and a significant  
19 component of overall burden of care. They developed a range of practical strategies to  
20 address feeding and nutrition challenges, including supervising meal times, avoiding  
21 disagreements over food and providing regular snacks and finger foods.

22 **Conclusions:** Family carers feel unsupported and uninformed with respect to nutrition-  
23 related care of individuals with dementia. Health professionals need to enhance the support  
24 and education provided to family carers, including recommending low-risk strategies that  
25 have been tried and tested by experienced family carers.

26 **Keywords (MeSH):** caregivers, dementia, diet therapy, family, nutritional support.

## 27 **Introduction**

28 Dementia is a syndrome characterised by a progressive impairment of brain function,  
29 including language, memory, perception, personality and cognitive skills.<sup>1, 2</sup> Approximately  
30 35 million people currently live with dementia globally, and the prevalence is predicted to  
31 triple by 2050.<sup>1</sup> Although dementia is not a normal part of ageing, the likelihood of  
32 developing dementia increases considerably with age.<sup>1</sup> Australia's ageing population  
33 represents a significant challenge for Australia's health care system, and dementia has been  
34 recognised as a national health priority area.<sup>3</sup>

35 Studies investigating the relationship between nutrition and dementia have included  
36 considerations of the role of nutrition in dementia aetiology, dementia management and  
37 the prevention of progressive decline in nutrition status.<sup>4, 5</sup> There is limited evidence  
38 regarding the role of nutrition in dementia aetiology;<sup>6, 7</sup> including evidence for interventions  
39 such as antioxidant supplementation and calorie restriction to delay the progression of  
40 dementia.<sup>4</sup> The sequelae of nutritional status deterioration associated with the progression  
41 of dementia are common, but individually variable.<sup>5</sup> The nutritional status deterioration  
42 may include weight loss, changes in taste and olfaction, anorexia, reduced food and fluid  
43 intake and associated nutrient deficiencies.<sup>5</sup> There is little evidence that nutrition  
44 interventions improve the length of survival amongst people with dementia.<sup>8</sup> However, the  
45 objectives of nutrition support and nutrition-related care for dementia often include a  
46 reduction of malnutrition-related morbidity, such as maintaining immune-competence,  
47 muscle strength and mobility, and enhancing quality of life.<sup>1</sup>

48 Individuals living with dementia require significant amounts of care and support, with the  
49 type and level of care evolving as the disease progresses. The majority of older people with  
50 dementia live in the community and family members are considered to be the most  
51 common providers of care.<sup>1</sup> In Australia, it is estimated that family carers provide more than  
52 80% of support for people with a disability, including individuals with dementia.<sup>9</sup> Dementia  
53 care is widely acknowledged as being challenging and demanding, creating physical,  
54 emotional and financial stress on families.<sup>10</sup> In addition, family carers are predisposed to  
55 depression and psychological co-morbidity,<sup>11</sup> indicating that strategies designed to support  
56 carers are imperative.

57 More than half of individuals living with dementia lose some ability to feed themselves,  
58 creating a significant challenge for family carers.<sup>12</sup> Individuals living with dementia often  
59 experience unintentional weight loss and subsequently are at risk of malnutrition.<sup>13</sup>  
60 Nutritional status can be compromised by impaired appetite, dysphagia, forgetting and/or  
61 refusing to eat and poor food safety practices.<sup>14, 15</sup> Weight loss, as a proxy indicator for  
62 energy imbalance, may also be attributed to increased energy expenditure (pacing,  
63 wandering) and/or metabolic disturbances associated with the disease process.<sup>16</sup> For  
64 individuals living with dementia, weight loss is associated with decreased mobility and a  
65 reduction in activities of daily living.<sup>17</sup> When weight loss extends to  $\geq 3\%$  of body mass, an  
66 exacerbation of the disease process, such as cognitive impairment, can occur.<sup>5</sup> These  
67 complications can place further burden on individuals and their family carers.<sup>18, 19</sup> In  
68 addition, poor dietary intake and observations of weight loss and wasting have the potential  
69 to create significant anxiety amongst family carers as they attempt to address insufficient  
70 dietary intake.

71 There is limited literature on effective strategies to optimise the dietary intake of individuals  
72 living with dementia, with most focusing on direct nutrition interventions with the individual  
73 living with dementia. The four main strategies previously investigated relate to nutritional  
74 supplements, behaviour-based eating programs, inclusion of specific foods in the diet and  
75 training of family carers.<sup>20</sup> Nutrition education interventions for family carers have been  
76 developed in response to the perception by family carers that they lack information  
77 regarding strategies that optimise the nutrition intake of individuals living with dementia.<sup>15</sup>  
78 These interventions have been shown to reduce the risk of malnutrition and weight loss in  
79 individuals living with dementia.<sup>21, 22</sup>

80 Further investigation of nutrition support strategies and carers' experiences of nutrition  
81 support are warranted due to the high prevalence of dementia care, the likelihood of  
82 experiencing food and nutrition support challenges, and the potential contribution of  
83 nutrition support strategies on carer burden. The aim of this study was to explore the  
84 perceptions of family carers of individuals with dementia, with particular emphasis on  
85 feeding and nutrition challenges, burden of care attributable to nutrition support and  
86 practical strategies developed by family carers to address these challenges. This  
87 investigation will improve our understanding of family carers' experiences of nutrition

88 support in dementia care, and has the potential to identify effective nutrition support  
89 strategies that have utility for other family carers if shared.

90

91 **Methods**

92 The qualitative study was informed by a descriptive exploratory approach,<sup>23, 24</sup> describing  
93 family carers' reflections on their experiences of caring for an individual with dementia, with  
94 a particular emphasis on nutrition-related care. A semi-structured qualitative interview  
95 design was employed, utilising open-ended questions to guide interviews. Interview  
96 questions were informed by a review of published literature using an inquiry logic that  
97 reflected the investigative aims of the study. Table 1 outlines each question, including the  
98 inquiry logic for each question. The study received ethical approval from the *[removed for*  
99 *blinded review]* Human Research Ethics Committee.

100 **INSERT TABLE ONE ABOUT HERE**

101 Potential participants were English-speaking male and female individuals aged  $\geq 18$  years  
102 who were current or recent family carers (within last 6 months) of a person living with  
103 dementia and living in Queensland, Australia. Mixed-strategy purposive and snowball  
104 sampling were utilised to recruit participants. Information about the study was included in  
105 newsletters distributed by associated organisations (Alzheimer's Australia and Victoria RSL),  
106 and on Alzheimer's Australia's Facebook and Twitter websites. Specific individuals known to  
107 the research team were contacted to assist in recruitment using existing carer networks.  
108 Interested participants were asked to contact the research team to receive further  
109 information, provide informed consent and arrange an individual interview. All family carers  
110 who contacted the research team ultimately participated in the study.

111 Interviews were conducted in 2012 by a researcher who had no prior relationships with the  
112 participating carers. Interviews were conducted via telephone using the interview questions  
113 described in Table 1, at a time convenient to the participant. Interviews were recorded with  
114 participants' permission, and transcribed verbatim by one interviewer (SJ). After each  
115 interview, participants were asked whether they knew of anyone else that may be eligible  
116 and interested in volunteering for the study. Data collection and analysis were conducted  
117 simultaneously, and participant recruitment continued until saturation of response themes  
118 was considered to have been achieved by the interviewer. In practical terms, saturation was  
119 considered to have been reached when no new response themes were detected as  
120 interviews progressed.

121 Analysis of verbatim transcripts involved an iterative process of data reduction, systematic  
122 comparison and conclusion.<sup>25</sup> Transcript data was thematically analysed using a process of  
123 open-coding involving responses being read through, re-read, coded using an iterative  
124 coding list developed during the analysis and organised within theme categories.<sup>23, 24</sup>  
125 Triangular analysis was conducted by three investigators (LB, SJ, RH) by independently  
126 coding and sorting interview data, and then comparing and discussing the themes to reach  
127 agreement about common and uncommon response themes. Example quotes have been  
128 included to support key and/or contradicting themes identified.

129 **Results**

130 Fourteen individuals (aged  $58\pm 17.8$  years, range 25 to 85) were interviewed as family carers  
131 for fourteen people with dementia (aged  $78\pm 11.2$  years, range 54 to 91). Two male carers  
132 were caring for their wives and the female carers were caring for husbands (4), fathers (3) or  
133 mothers (5). The family carers interviewed had been in a caring role ranging from 1 year to  
134 14 years (mean  $\sim 5$  years), and the proportion of their time spent in overall care ranged from  
135 occasional assistance through to total supervision and care during waking hours. Most of  
136 the family carers had been involved in feeding and nutrition-related care from the outset of  
137 the caring period for the individual with dementia; however this was reported by most to  
138 have increased as the condition progressed.

139 Family carers described a range of feeding-related challenges experienced during the care of  
140 their relative. The challenges have been broadly categorised as physiological, cognitive,  
141 emotional, functional and/or behavioural (Table 2). Cognitive challenges were most  
142 common, including the person in care being forgetful, disorientated or confused and  
143 needing considerable care and support with feeding. Physiological challenges were also  
144 frequently reported by family carers, including swallowing difficulties, loss of appetite and  
145 changes in food preferences. Emotional barriers included social isolation, not wanting to be  
146 fed by another person, possessiveness, and the person with dementia becoming frightened.  
147 These emotional barriers often contributed to behavioural challenges such as anger and  
148 aggression, or the hoarding of food and cutlery. Functional challenges included difficulties  
149 using cutlery and visio-spatial issues such as not recognising food.

150 **INSERT TABLE TWO ABOUT HERE**

151 Table 2 summarises the key themes relating to feeding challenges and the strategies  
152 employed by family carers to maintain or enhance food intake. Family carers' descriptions  
153 of the strategies they used to address feeding challenges indicated that patience and  
154 persistence with care were central themes. The challenges often required an approach that  
155 avoided confrontation, diffusing feeding-related anxiety at the point in time, followed soon  
156 after by repeated attempts to encourage eating. Many family carers commented that this  
157 persistence worked but required a lot of patience. The importance of, and burden  
158 associated with, feeding time supervision was also a common response theme.

159 *“Just allow her time to eat, exercising a bit more patience.”* (Participant 1, 29 year old  
160 female family carer)

161 *“I eat each time he eats; otherwise it’s a battle to get him to eat alone.”* (Participant 12, 62  
162 year old female family carer)

163 Family carers perceived that it was important to recognise and accommodate the specific  
164 taste preferences of their relative in order to ensure adequate food intake. These taste  
165 preferences often required family carers to change and develop their food preparation  
166 practices to suit their relative.

167 *“The best way to cope with it was to let her be the boss and cook the way she wanted me to,  
168 and not to push with my knowledge of what was healthy or not.”* (Participant 2, 62 year old  
169 female family carer)

170 *“We agreed that I will cook two types of food, one for her and one for me.”* (Participant 2, 62  
171 year old female family carer)

172 Family carers often reported developing a number of psycho-social approaches to  
173 encourage food intake. These strategies included families sitting to eat together, having  
174 plenty of time for a meal and maintaining socialisation with friends at meal times. Some  
175 family carers developed strategies such as minimising distractions at meal times or  
176 preparing for meals using the same routine each time, which were perceived to enhanced  
177 food intake. Others developed food presentation strategies such as serving small and  
178 numerous portions in one meal, cutting food into small pieces and using finger foods.

179 *“We found that if we sat with him to eat, you know eating is a social thing, a social  
180 experience. So we sat alongside him and had a cuppa while he had his breakfast and that  
181 really helped.”* (Participant 10, 58 year old female family carer)

182 Family carers’ experiences and observations of weight changes amongst relatives during  
183 their care were varied; however a majority (8/14) reported some weight loss. Weight loss  
184 was generally attributed to general decline, part of the disease process, low food intakes  
185 and in a number of cases specifically attributed to energy imbalance associated with  
186 excessive wandering. Only two of the family carers reported noticing weight gain, but



187 appeared unconcerned because the gain was due to appropriate nutrition-related care and  
188 support, often rectifying previous weight losses.

189 Most family carers reported that they were initially uninformed about expected weight  
190 changes related to dementia and had received little guidance from health professionals. A  
191 small number of family carers who had health professional backgrounds were aware of the  
192 potential for weight loss accompanying dementia and a few reported that they had learnt  
193 about nutrition and feeding strategies through their own investigations.

194 *“[Weight loss] has never arisen at any of our meetings or anything. And it has never really*  
195 *come up with the GP [General Practitioner] or [the specialist] or anything.”* (Participant 14,  
196 85 year old male family carer)

197 *“From being an RN in aged care for many years and also having a special interest in*  
198 *dementia – I worked with Alzheimer’s Association years ago, I know they do lose weight over*  
199 *time as a part of the disease”* (Participant 5, 65 year old female family carer).

200 Rapid weight loss that manifested as noticeable wasting was a source of considerable  
201 anxiety by most family carers. A feeling of failure, helplessness and a significant source of  
202 emotional stress often accompanied this anxiety.

203 *“I just went to pieces when she lost weight. I still go to pieces...she was so skinny and bony*  
204 *and unhappy.”* (Participant 2, 62 year old female family carer)

205 For many family carers, these feelings appeared to be compounded by a lack of information  
206 and support specific to feeding strategies and weight loss. One family carer, with a  
207 background as a registered nurse, described her anxiety and challenge dealing with her  
208 relative’s weight loss as *“being the biggest challenge of my life”* (Participant 10, 58 year old  
209 female family carer). This example highlights the potential impact the sequelae of events in  
210 dementia care (difficulties feeding, weight loss, carer anxiety) can have on family carers,  
211 even with health care experience.

212 Some family carers discussed the use of food-based strategies to address weight loss, such  
213 as providing more nutrient-dense foods, high energy and protein supplement drinks and/or  
214 adding calorie dense ingredients to normal foods (e.g. butter, cream). Other strategies to

215 respond to weight loss mirrored strategies utilised to respond to feeding-related challenges,  
216 and are described in Table 2.

217 Whilst most family carers reported that their initial knowledge and awareness of nutrition-  
218 specific issues related to dementia care was low, most had increased their knowledge and  
219 awareness through observational learning and trial and error. Support groups and online  
220 tools were common sources of information when family carers proactively took steps to be  
221 more informed. Most of the family carers reflected that there was little to no education and  
222 guidance offered to them by health professionals regarding specific nutrition or feeding  
223 issues associated with dementia. Family carers also perceived that there was no training  
224 available about nutritional needs for people with dementia or about methods for ensuring  
225 adequate food intake. At family carers' meetings (support groups or association meetings),  
226 behavioural issues were a common topic of discussion. Although behavioural issues were  
227 considered to be heightened during meal times, strategies for improving food intake at meal  
228 times or making meals easier were not the focus of discussions.

229 Several family carers found that they had a difficult time accessing nutrition support  
230 resources, such as nutrition supplements, largely because of costs. Almost half (6/14) of the  
231 family carers mentioned a dietitian as a possible source of nutrition support when they were  
232 asked about their knowledge of nutrition and dementia, five of whom stated their relative  
233 had never been referred to a dietitian by any health professional.

234 *"I could not get supplementation as a person living in the community. The only thing I could*  
235 *get was Sustagen and it was costing an arm and a leg. I phoned the companies that produce*  
236 *the supplements. None of them would supply me as an individual; it had to come via an*  
237 *organisation."* (Participant 10, 58 year old female family carer)

238 When asked to identify support required to reduce the burden of nutrition care, responses  
239 tended to relate to practical relief (such as 'Meals on Wheels') or support that addressed  
240 anxiety associated with a lack of knowledge and skills relating to nutrition support (such as  
241 access to a dietitian). Access to other family carers with 'real world' experience dealing with  
242 feeding difficulties and providing nutrition-related support was considered highly valuable  
243 to family carers.

244 *“Maybe a dietitian who has special training in dementia would be useful.”* (Participant 8, 52  
245 year old female family carer)

246 *“Seeing a dietitian once every 6 months or a year for an assessment of their needs, how to  
247 interest them in food, and suggestions for preparing food.”* (Participant 8, 52 year old female  
248 family carer)

249 *“The one thing I found difficult to find was other family carers getting together to talk about  
250 food issues. That’s where you are going to get good information from, advice on what is  
251 working and what you can do in certain situations; people who have been there before.”*  
252 (Participant 9, 33 year old female family carer)

253 When prompted, participants shared lessons from their own experience as family carers  
254 that they perceived would be paramount for new family carers to know as they began their  
255 journey as a carer. The key response themes from this shared wisdom are summarised in  
256 Table 3.

257 **INSERT TABLE THREE ABOUT HERE**

258 Most family carers reflected that their experience of nutrition care had been difficult and a  
259 significant component of their experience of overall burden of care. Family carers reported  
260 experiencing numerous emotions during their time providing nutrition-related care. This  
261 included anxiety, stress and worry that the way they were caring was not ‘correct’, or that  
262 their relative was reliant solely on them for food, nutrition and eating. Overall, family carers  
263 found nutrition-related care to be a significant challenge, at times frustrating, and often left  
264 them feeling distressed. Responses suggest that nutrition-related care had been a major  
265 contributor to overall burden of care in this sample.

266 *“It was time consuming and draining because you had to be there and concentrating. It took  
267 an hour to feed her. It was a big challenge.”* (Participant 1, 29 year old female family carer)

268 *“You never really have a break. You never feel free to actually go and do anything, or stay  
269 overnight anywhere without a whole lot of planning and packing.”* (Participant 13, 68 year  
270 old female family carer)

271 *“Now that he is in care, I can relax more and I enjoy the quality time we spent together now.”*

272 *(Participant 5, 65 year old female family carer).*

## 273 Discussion

274 The aim of this study was to investigate the perceptions of family carers on their experience  
275 of providing feeding and nutrition-related support to individuals living with dementia.  
276 Family carers described a range of feeding-related challenges categorised as physiological,  
277 cognitive, emotional, functional and/or behavioural challenges. The strategies developed for  
278 overcoming these challenges were highly varied. Overall, the participants found feeding and  
279 nutrition support to be a significant challenge, and this aspect of care appeared to be a large  
280 source of burden for family carers.

281 The family carers reported that the burden associated with nutrition-related care was  
282 significant, yet difficult to quantify in the context of broader conceptualisations of carer  
283 burden. Family carers felt uninformed regarding feeding challenges, which resulted in family  
284 carers feeling anxious and distressed, and contributed to their feeling of significant burden  
285 associated with the care of their relative. This finding is in line with recent literature that  
286 suggests that family carers feel overwhelmed and stressed when provided with inadequate  
287 resources, or resources that are inappropriate to their level of medical knowledge, or do not  
288 adequately resolve their ongoing problems.<sup>14</sup> Therefore, the educational resources and  
289 support provided to family carers needs to incorporate practical (and where possible carer-  
290 tested) strategies to ensure that appropriate and sufficient support is provided to family  
291 carers to ameliorate the burden associated with feeding and nutrition-related challenges.

292 Participating family carers felt they had not received adequate information and support  
293 from health professionals or carer groups about nutrition-related care. Evidence from  
294 earlier studies also suggest that the nutrition-related resources provided to family carers are  
295 usually of low quality and do not address the concerns of family carers.<sup>14, 15</sup> This evidence of  
296 inadequate information and support suggests a need for strategies and services focusing on  
297 family carer education. Family carer education has previously been a focus of nutrition-  
298 related interventions for individuals living with dementia,<sup>22</sup> including the provision of carer  
299 support.<sup>20</sup> Interventions such as these have successfully improved the rate of malnutrition  
300 of individuals living with dementia.<sup>21</sup> Notably, none of these interventions have been  
301 implemented and evaluated in the Australian setting, and the potential for improving the

302 education provided to family carers requires consideration and collaboration between  
303 health professionals and relevant health organisations.

304 The feeding and nutrition-related challenges faced by family carers in this study varied  
305 considerably, reflecting earlier studies.<sup>13, 26, 27</sup> This variability makes the development of  
306 guidance resources that meet the general needs of family carers challenging, and generic  
307 advice for family carers regarding nutrition may not be useful.<sup>28</sup> Instead, health  
308 professionals and services should work in partnership with family carers to focus on  
309 identifying nutrition-related strategies that meet the individual needs of family carers and  
310 their relative, and focus on the range of factors that make feeding support challenging.  
311 These partnerships between health professionals and family carers can be enhanced by  
312 sharing other family carers' practical and field tested strategies, such as those identified in  
313 this sample of carers. The recommendation of such strategies should be appropriately  
314 assessed by qualified health professionals as causing no harm before broader dissemination.

315 It is noticeable that the strategies identified as commonly developed in this sample of family  
316 carers are low risk in terms of nutrition or broader health status, and focus on practical  
317 behavioural management strategies. This finding is probably not unexpected given the  
318 nature of the investigation into the family carers' perceptions of their experiential learning,  
319 and the prevalence of behavioural challenges associated with dementia that impact on  
320 feeding support. However, this study has some limitations in terms of the generalisability of  
321 findings to other family carers. The participants' varied experience and currency of  
322 dementia care (in terms of duration, reflections of caring now or in the past) may have  
323 contributed to the variability of experience with regards to challenges observed, strategies  
324 developed and the effects of feeding care on family carer burden. However, this study has  
325 not aimed to collect data to represent a shared experience across all family carers, but  
326 instead amongst a purposively sampled, information rich sample.

327 The emphasis and value given to carers' field tested strategies and other lay knowledge in  
328 this study is based on the assumption that family carers can, and will, develop knowledge  
329 and solutions to problems they experience. We are unable to confirm the extent to which  
330 the strategies described by the current participants were developed independently of health  
331 professionals and in situations of limited health professional support. The present results

332 therefore do not assume the strategies developed by family carers are effective or indeed  
333 safe, but simply worthy of note and consideration. It is advised that these strategies are  
334 assessed for risk of potential harm, and if appropriate, be shared with other family carers.

335 In conclusion, family carers of people with dementia experience a wide and individually  
336 variable range of issues surrounding feeding and nutrition-related support. Family carers  
337 have developed a range of strategies to deal with these challenges, worthy of dissemination  
338 amongst other family carers after being assessed for risk. The family carers in this study  
339 reported lacking appropriate information, support and guidance, which contributed to their  
340 perception of feeding-related burden of care.

341

342 **References**

- 343 1. World Health Organization, Alzheimer's Disease International. Dementia: a public health  
344 priority. Geneva 2012.
- 345 2. Australian Institute of Health and Welfare. Dementia in Australia: National data analysis and  
346 development. Canberra 2007.
- 347 3. Australian Institute of Health and Welfare. Health priority areas. Australian Government;  
348 2012; Available from: <http://www.aihw.gov.au/health-priority-areas/>.
- 349 4. Keller H, Bocock M. Nutrition and dementia: clinical considerations for identification and  
350 intervention. *Neurodegenerative Disease Management* 2011;1:513-22.
- 351 5. Hanson L, Ersek M, Gilliam R, Carey T. Oral feeding options for people with dementia: a  
352 systematic review. *J Am Geriatr Soc* 2011;59:463-72.
- 353 6. Wimo A, M Prince. World Alzheimer Report 2010 Alzheimer's Disease International 2010.
- 354 7. Luengo-Fernandez R, Leal J, Gray A. Dementia 2010: The prevalence, economic cost and  
355 research funding compared with other major diseases. Executive summary: Health Economics  
356 Research Centre, University of Oxford, UK 2010.
- 357 8. Palecek E, Teno J, Casarett D, et al. Comfort feeding only: a proposal to bring clarity to  
358 decision-making regarding difficulty with eating for persons with advanced dementia. *J Am Geriatr*  
359 *Soc* 2010;58:580-4.
- 360 9. Access Economics. The economic value of informal care. Report for Carers Australia.  
361 Canberra 2005.
- 362 10. World Health Organization. Dementia Fact Sheet. Geneva 2012; Available from:  
363 <http://www.who.int/mediacentre/factsheets/fs362/en/index.html>.
- 364 11. Seeher K, Low LF, Reppermund S, Brodaty H. Predictors and outcomes for caregivers of  
365 people with mild cognitive impairment: A systematic literature review. *Alzheimer's & Dementia* 2012.
- 366 12. LeClerc C, Wells D, Sidani S, Dawson P, Fay J. A feeding abilities assessment for persons with  
367 dementia. *Alzheimers Care Quarterly* 2004;5:123-33.
- 368 13. Rullier L, Lagarde A, Bouisson J, Bergua V, Barberger-Gateau P. Nutritional status of  
369 community-dwelling older people with dementia: associations with individual and family caregivers'  
370 characteristics. *Int J Geriatr Psychiatry* 2012.
- 371 14. Keller H, Smith D, Kasdorf C, et al. Nutrition education needs and resources for dementia  
372 care in the community. *American Journal of Alzheimer's Disease and Other Dementias* 2008;23:13-  
373 22.
- 374 15. Shatenstein B, Kergoat M, Chicoine M. Dietary intervention in older adults with early-stage  
375 Alzheimer dementia: early lessons learned. *Journal of Nutrition, Health and Ageing* 2008;12:461-9.
- 376 16. Knopman D. Go to the head of the class to avoid vascular dementia and skip diabetes and  
377 obesity. *Neurology* 2008;71:1046-7.
- 378 17. White H, Pieper C, Schmader K. The association of weight change in Alzheimer's disease with  
379 severity of disease and mortality: a longitudinal analysis. *J Am Geriatr Soc* 1998;46:1223-7.
- 380 18. Grundman M. Weight loss in the elderly may be a sign of impending dementia. *Arch Neurol*  
381 2005;62:20-2.
- 382 19. Wolf-Klein G, Silverstone F, Levy A. Nutritional patterns and weight change in Alzheimer  
383 patients. *Int Psychogeriatr* 1992;4:103-18.
- 384 20. Burgener S, Buettner L, Coen Buckwalter K, et al. Evidence supporting nutritional  
385 interventions for person in early stage Alzheimer's Disease (AD). *Journal of Nutrition, Health and*  
386 *Ageing* 2008;12:18-21.
- 387 21. Salva A, Andrieu S, Fernandez E, et al. Health and nutritional promotion program for patients  
388 with dementia (NutriAlz Study): design and baseline data. *Journal of Nutrition, Health and Ageing*  
389 2009;13:529-37.



- 390 22. Riviere S, Gillette- Guyonnet S, Voisin T, et al. A nutritional education program could prevent  
391 weight loss and slow cognitive decline in Alzheimer's disease. *Journal of Nutrition, Health and Ageing*  
392 2001;5:295-9.
- 393 23. Smith J, Flowers P, Larkins M. *Interpretative Phenomenological Analysis. Theory, Method and*  
394 *research*. London: Sage Publications 2009.
- 395 24. Fade S. Using interpretative phenomenological analysis for public health nutrition and  
396 dietetic research: a practical guide. *Proc Nut Soc* 2004;63:647-53.
- 397 25. Miles M, Huberman A. *Qualitative data analysis*. 2nd Ed. London: Sage publications; 2004.
- 398 26. Mitchell SL, Teno JM, Kiely D, et al. The clinical course of advanced dementia. *N Engl J*  
399 *Med* 2009;361:1529-38.
- 400 27. Silva P, Kergoat M, Shatenstein B. Challenges in managing the diet of older adults with early-  
401 stage Alzheimer dementia: a caregiver perspective. *The Journal of Nutrition, Health & Aging*  
402 2013;17:142-7.
- 403 28. Cole D. Optimising nutrition for older people with dementia. *Nursing standard (Royal College*  
404 *of Nursing (Great Britain)* 2012;26:41.

405